

**Genetic Privacy, Discrimination and Research in Washington State:
Findings, Conclusions and Recommendations of the
Washington State Board of Health Genetics Task Force
DRAFT REPORT 6-18-02**

Introduction

The 2001-2003 Washington state biennial operating budget (ESSB 6153) passed by the State Legislature in June 2001 included a proviso (Sect. 220.8) for the State Board of Health (BOH) to convene a broad-based task force to “review the available information on the potential risks and benefits to public and personal health and safety, and to individual privacy, of emerging technologies involving human DNA.” The budget proviso directed this task force to consider four areas related to genetic privacy and discrimination in Washington state: 1) incidence of discriminatory actions based upon genetic information; 2) strategies to safeguard civil rights and privacy related to genetic information; 3) remedies to compensate individuals for inappropriate use of genetic information; and 4) incentives for further research and development in the use of DNA to promote public health, safety and welfare. In addition, the Genetics Task Force (GTF) also reviewed existing Newborn Screening (NBS) Program privacy policies. The GTF consisted of 22 members and met five times over a nine-month period between January 2002 and September 2002. The GTF heard, reviewed, and discussed many aspects of privacy, discrimination, and research with respect to genetic information. This report summarizes the findings, conclusions and recommendations of the GTF.

Background

Legislative History

The Washington State Legislature considered 25 different drafts of various genetics-related legislation between January 1998 and March 2002. These drafts included legislation related to criminal DNA databases, health insurance, informed consent, misuse of genetic information, the definition of health care information, and genetic testing. See Table X for a summary of the proposed legislation. Sixteen of the proposed bills specifically addressed privacy or discrimination issues with respect to genetics. In March 2002 the Legislature passed ESSB 5207, which amended RCW 70.02 to add a person’s deoxyribonucleic acid (DNA) and identified sequence of chemical base pairs to the definition of ‘health care information’. This legislation

provides DNA with the same privacy protections as other health care information in the state of Washington.

Additional legislative activity concerning genetics included Section 220(8) of the 2001-2003 Washington State biennial operating budget. A proviso in this budget directed the BOH to create a broad-based task force to “review the available information on the potential risks and benefits to public and personal health and safety, and to individual privacy, of emerging technologies involving human DNA.”

GTF Work Plan

In response to the directive contained in the 2001-2003 biennial operating budget, the BOH staff drafted a Work Plan for selecting members, establishing the GTF, convening meetings, and drafting a report. The BOH approved the Work Plan in October 2001. See Appendix X for a copy of the Work Plan.

The Work Plan adopted by the BOH defined the scope of the GTF as set forth in the legislative proviso. The legislature and the BOH asked the GTF to consider the potential of genetic information to advance scientific knowledge and improve health care practice in the context of privacy and discrimination concerns and to consider potential regulations regarding the use of and access to genetic information. The scope of the GTF included the collection, storage, and sharing of genetic information within the health and medical care systems. Also included in the scope of the GTF was the use of genetic information in the context of health, life and disability insurance and employment as balanced against the risk of harm to scientific research and development that can potentially benefit public health, safety, and welfare. The GTF did not consider issues related to stem cell research and cloning.

Selecting GTF Members

The BOH invited representatives from the following interests to be members of the GTF: state and local public health, public and private purchasers of medical care, health insurance carriers, primary care physicians, pathology and laboratory medicine, genetic counselors, hospitals, genetic ethicists, institutional review boards, research geneticists, trial attorneys, medical research institutions, civil rights advocates, privacy advocates, citizens who have undergone genetic testing, parents whose children have been helped by genetic testing, the

biotechnology industry, and experts in privacy laws and rules such as HIPAA. The BOH first invited individuals who were presently or previously involved with existing BOH or Department of Health (DOH) genetics committees such as the Newborn Screening Advisory Committee, the Pre-natal Screening Advisory Committee, and the DOH's Genetic Services Advisory Committee. Other members were selected from relevant professional societies and associations. If the invited person was not available to serve on the GTF, that person was asked to nominate a replacement. A list of GTF members is provided in Table X.

Methods

Collecting Information

BOH staff scheduled 5 meetings for the GTF over the course of nine months. Three of these meetings were held to hear from experts on specific topics such as existing legislation that may encompass the privacy of genetic information, the use of genetic information for insurance purposes, and the state of genetic research and development in Washington. Table X summarizes the topics covered at each meeting. The GTF staff supplemented information received at the meetings through literature and legislative research and consultation with legal and/or policy advisors. Summaries of staff research were presented to the GTF in the form of meeting summaries, a matrix and a glossary. The matrix and glossary are included with this report as Appendices X and Y.

The last two meetings served as opportunities for GTF members to present and discuss their conclusions and recommendations based on the information received at the first three meetings and to discuss, review and edit drafts of the final report.

Subcommittees

Prior to the fourth GTF meeting, members identified four specific areas for deliberations and divided into four subcommittees to review the available information in each area, draw conclusions from this information, and make recommendations based on their conclusions.

Subcommittee One considered the use of genetic information in the health care setting. Specifically, this subcommittee identified and analyzed three areas related to the use of genetic information in the health care setting: a) diagnosis of symptomatic conditions; b) reproductive decisions; and c) predictive identification of genetic risk factors for late-onset diseases.

Subcommittee Two considered issues related to state mandated DNA collection and/or genetic testing. This subcommittee looked at existing systems and policies such as the Newborn Screening Program and criminal DNA databases. Subcommittee Three addressed issues surrounding genetic research. Specifically, this subcommittee examined the use of genetic information in academic and basic science, public health, and biotechnology industry research. Subcommittee Four addressed the use of genetic information for other social purposes including health, life, and disability insurance and employment.

Table X Proposed Genetic Legislation in Washington State

Number	Year	Title	Sponsor	Summary
SB 5298	1998		Senator Franklin	This bill protects genetic information from health insurance discrimination, and defines genetic information as information about genes, gene products, or inherited characteristics. (see SB 6663, 1998)
SB 6663	1998		Senator Franklin	This bill prohibits insurer discrimination in coverage or benefits on the basis of genetic information, and employer discrimination on the basis of genetic information. Additionally, it protects the right of an individual to refuse to disclose genetic information, and it creates a cause of action for violation of the provision. Genetic information is defined as information about inherited characteristics.
HB 1757	1999	DNA Data Base--Violent and Sex Offenders Effective Date: 7/25/99	Representative Miloscia	Enacted, 1999. Provides that every juvenile or adult convicted of a violent or sexual felony shall have blood drawn for purposes of DNA identification analysis. A purpose of the legislation is to create an expanded DNA data bank for use in law enforcement. The act amends RCW 43.43.754, and creates a new section.
HCR 4412	1999	DNA Technology	Representative Miloscia	Adopted, 1999. The resolution establishes a joint select committee on DNA identification to review the following: DNA use, DNA identification, DNA testing, DNA data banking, DNA technology, DNA research, and DNA privacy issues. After reporting its findings to the legislature, the committee expires July 1, 2000.

Table X continued Proposed Genetic Legislation in Washington State

SB 5111	1999	Health Insurance Discrimination	Senator Franklin	This version of the bill prohibits health insurance discrimination on the basis of genetic information. It declares that a health carrier may not deny or cancel health plan coverage or vary the premiums, terms, or conditions for coverage, for an individual or a family member of an individual either 1) on the basis of genetic information, or 2) because the individual or family member of an individual has requested or received genetic services. It additionally prevents a health carrier from requesting disclosure of individual's genetic information, and it also prevents the health carrier from disclosing any genetic information about an individual without his consent.
ESSB 5111	1999	Health Insurance Discrimination		This bill is very similar to SB 5111 described above. It adds three limited situations in which a health carrier may disclose a patient's genetic information: research, internal use for family genetic counseling, and newborn screening authorized by 70.83 RCW.
HB 2491	2000	DNA--Postconviction Testing Effective Date: 6/8/00	Representative Schindler	Enacted, 2000. Allows persons sentenced to death or life imprisonment to request deoxyribonucleic acid testing of evidence in their case. This act relating to DNA testing of evidence, amends RCW 10.37.050, adds a new section to RCW 10.73, and creates new sections.
HB 2732	2000	DNA Identification System	Representative Miloscia	This bill provides for collection of blood samples for DNA identification from convicted felons. It finds that the DNA identification system is increasingly useful in the accurate investigation and prosecution of criminal offenses, and determines that it is in the public interest to expand the DNA identification system to include all convicted felons.

Table X continued Proposed Genetic Legislation in Washington State

HB 2861	2000	Health Care Information Definition	Representative O'Brien	This bill modifies the definition of "health care information" to explicitly include "a patient's deoxyribonucleic acid and identified sequence of chemical base pairs".
SB 6203	2000	Institutional Review Boards	Senator Fairley	This bill provides requirements for the composition of institutional review boards, and relates to health facility oversight.
SB 6284	2000	Protection of DNA Information	Senator Hargrove	This bill, as originally introduced, protects DNA identification information, specifically data collected during criminal investigations of suspects who were not convicted, or juvenile victims or offenders. As substituted in Jan., 2000 this bill sets up a DNA commission to evaluate issues relating to use and protection of DNA information.
SB 6326	2000	Insurance Transactions	Senator Franklin	This bill prevents a person's DNA from being screened for any insurance transaction.
SB 6327	2000	Genetic Discrimination	Senator Franklin	This bill prevents genetic discrimination using "information obtained from interpreting the sequence of chemical base pairs in a person's deoxyribonucleic acid". It amends RCW 49.60.
SB 6340	2000	Civil Action	Senator Franklin	This bill creates a civil action for improperly obtaining a persons DNA.
SB 6341	2000	Informed Consent	Senator Franklin	This provision requires informed consent before obtaining a person's DNA. It specifies requirements for informed consent, and it lists circumstances in which informed consent is not needed.
SB 6395	2000	DNA Technology Issues Commission	Senator Franklin	This bill establishes a commission to study issues involving deoxyribonucleic acid technology.

Table X continued Proposed Genetic Legislation in Washington State

ESSB 6395	2000	DNA Technology Issues Commission	Senator Franklin	In addition to establishing a commission, this bill prevents screening of a person's DNA in an insurance transaction, it prevents discrimination regarding DNA screening in employment, it requires informed consent before isolating DNA for identification purposes, and it extends the commission for five years.
SB 5207	2001	Individually Identifiable DNA Testing	Senator Hargrove	This bill relates to individually identifiable DNA testing. It redefines health care information to include "genetic test information from a person's isolated DNA and a person's DNA when obtained at the request of a health care provider or health care facility." The bill also sets up a commission to report by July 1, 2002 on issues including use and misuse of DNA and genetic information, genetic privacy, and genetic discrimination.
SB 5282	2001	DNA Use in Insurance Transactions	Senator Franklin	This bill prevents insurers from "screening" an individual's DNA. In this regard, it adds a new section to chapter 48.01 RCW.
SB 5283	2001	Discriminatory Use of DNA in Employment Matters	Senator Franklin	This bill expands on the general right to be free from discrimination in employment on the basis of "race, ...sex...[or] disability", by adding a specific right to prevent employers from screening a person's DNA. It amends RCW 49.60.030.
SB 5284	2001	DNA Informed Consent	Senator Franklin	This bill requires informed consent prior to isolating DNA in a form that identifies an individual for the purposes of genetic testing. Informed consent must include specific elements, and the bill lists specific circumstances in which informed consent under this section is not required.
SB 5665	2001	Genetic Information	Senator Prentice	This bill declares that each person has a fundamental privacy interest in their genetic information. It also protects an individual's right to choose or refuse to release their genetic information.

Table X continued Proposed Genetic Legislation in Washington State

ESSB	2002	Health Care Information--DNA	Representative O'Brien	This bill amends RCW 70.02 by changing the definition of 'Health Care Information' to include a person's DNA. This bill passed the legislature in March 2002.
HB 2468	2002	An act relating to the convicted offender DNA data base	Representatives Miloscia, O'Brien and Wood	This bill expands the class of persons from whom DNA samples are taken to include persons convicted of: any felony; stalking; harassment; and communicating with a minor for immoral purposes. It also specifies that samples must be taken from persons convicted before the effective date of the act who are still incarcerated as of the effective date of the act. And it states that the method of collecting the samples is no longer limited to drawing blood only. This bill passed the legislature in March 2002.
SB 6473	2002	An act relating to the convicted offender DNA data base	Senators Hargrove, Long, Costa and Winsley	Companion bill to HB 2468

Full text, history, and digests of the House and Senate Bills summarized above may be found at the Washington State Legislature's website <<<http://www.leg.wa.gov>>>

Specific bills are indexed at the site by date and source:

e.g. SB 5298 is at: http://www.leg.wa.gov/pub/billinfo/1997-98/senate/5275-5299/5298_012297.txt

Table X GTF Members

Robin Bennett Representing- Genetic Counselors	Philip Bereano Representing the American Civil Liberties Union for Civil Rights Advocates
Dr. Wylie Burke Representing- Genetic Ethicists	Dr. Peter Byers Representing- Research Geneticists
Dr. Maureen Callaghan, MD Representing- Washington State Medical Association	Howard Coleman Representing- Biotechnology Industry
Amanda DuBois Representing- Trial Attorneys	Joe Finkbonner, R.Ph., MHA Representing- Washington State Board of Health
Nancy Fisher, MD, MPH, RN Representing- Health Insurance Carriers	Maxine Hayes, MD, MPH Representing- State Public Health
Vicki Hohner, MBA Representing- HIPAA and Agency Privacy Coordinator	Mellani Hughes, JD Representing- Private Purchasers of Medical Care
Linda Lake, Chair Representing- Washington State Board of Health	Helen McGough Representing- Institutional Review Board
Robert Miyamoto, PhD Representing- Citizens who have undergone genetic testing	Suzanne Plemmons, RN, MN, CS Representing- Local Public Health
Ree Sailors Representing- Public Purchasers of Medical Care	Julie Sando Representing- Parents whose children have been helped by genetic testing
Julie Sanford-Hanna, PhD Representing- Pathologists or Laboratory Medicine	C. Ronald Scott, MD Representing- Medical Research Institutions
Brenda Suiter Representing- Hospitals	Ty Thorsen Representing- Privacy Advocates

Table X Meeting Topics

Date	Topic
January 3, 2002	<ul style="list-style-type: none"> • Overview of Work Plan • Review of legislative history • Introduction to genomics • Newborn Screening Program laws and privacy policies • HIPAA and genetic privacy • Washington State Health Care Information Act • Institutional Review Board policies and guidelines
February 25, 2002	<ul style="list-style-type: none"> • Overview of insurance laws and policies with respect to genetics • Overview of genetic privacy and genetic discrimination • Historical perspectives: eugenics • Review of genetics related privacy and discrimination in other states • Overview of the effects of genetics privacy legislation on research in Oregon • Evidence of genetic discrimination and privacy violations in Washington state
April 12, 2002	<ul style="list-style-type: none"> • Perspectives on genetic research from academic, basic science, public health, and biotechnology industry researchers